

BBMRI.nl & Health-RI expert meeting 2021: The next step in making health data available for research.

#2 – Making data findable and linkable

The 2nd BBMRI & Health-RI expert session was held on Thursday September 23, focussing on various strategies to make health data linkable.

Dr. Jeroen Beliën (AmsterdamUMC) coordinated the session. Jeroen highlighted the latest developments in enabling findability of data by demonstrating the Health-RI COVID-19 NL metadata portal. Hospitals and studies can make their COVID-19 related studies searchable and findable on this portal. The metadata for making this possible is based on a CEDAR metadata model, making it possible to add collections through user friendly web forms as well as programmable interfaces. Importantly, the collected data are also accessible and readable for researchers as well as machines.

First, Prof. dr. Sabine Siesling explained the procedures that link IKNL (oncology) data with NIVEL (general practitioners) data to gather insight into long-term health and adverse effects after treatment of (breast) cancer ([PSCCR](#) project). They used a trusted third party to link the data and drafted a contract to specify the collaboration agreements between IKNL and NIVEL. Afterwards, Prof. dr. Edwin Cuppen presented his experiences in linking data within the [GENONCO](#) project, in which data from PALGA (pathology), Hartwig Medical Foundation (whole genome sequencing data), and the Dutch Cancer Registry (NKR) were linked. The presented activities undertaken prove that establishing a linking procedure scalable to multiple organizations instead of agreements between two partner organizations is very complex.

A total of 57 delegates from relevant parties attended the session. The discussion was very constructive and interactive; best practices were shared, and the hurdles encountered were brought up on the table. This session offered potential solutions, because unfortunately it still takes a lot of time and energy from researchers to be able to link data. Two big reasons for this complexity could be distilled: 1) GDPR makes it difficult to make straightforward linking possible because, for instance, BSN cannot be used, and linking data between sources needs to be done using unwieldy methods. 2) the data sources that need to be linked are not organised in a similar fashion and mapping between them is often not trivial. This makes it very cumbersome to actually link. These are topics that need to be addressed to enable data linkage in the future.

The report and link to the recording of the 1st expert meeting with Prof dr. Wiro Niessen (CTO Health-RI, ErasmusMC), Dr. Rob Hoofft (DTL) and Dr. Margreet Bloemers (ZonMw) coordinated by Jan-Willem Boiten can be found [here](#). The [3rd session](#) will take place on October 7 (online) from 13.00-14.30 pm, with presentations from Dr. Aletta Debernardi (PALGA) and Sandra van den Broek (HMF) on data access procedures. The session will be led by Prof. dr. Folkert van Kemenade (Erasmus MC).